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Treatment of defective newborns – a survey of paediatricians in Poland

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Authors' abstract

We report the results of a survey of the attitudes and practices of paediatricians in Warsaw, Poland, with respect to the treatment of infants born with severe handicaps. The results are compared with a similar survey conducted by Australian researchers (1). In the Polish medical community surveyed, unconditional respect for life is a dominant attitude. Our study has revealed a deeply-entrenched paternalistic attitude among Polish doctors and a strong unwillingness to distinguish between 'ordinary and extraordinary means' of prolonging life, as well as an ambivalent attitude towards legal regulations binding in Poland.

Doctors' attitudes towards the treatment of newborn infants with severe and irreversible handicaps have been a major topic in medical ethics for some time. Whatever philosophers and physicians suggest as the proper moral way of resolving emerging dilemmas, medical practice is the way it is. As far as we know, nobody has yet tried to survey Polish doctors' opinions on this question. We were granted permission from an Australian research team to use their questionnaire (1) for a similar study in Poland. We decided to compare our findings with those reported by the Australian team, who studied paediatricians and obstetricians in separate studies. In our survey we probed attitudes only of doctors working at neonatal and intensive-care departments, who usually have to decide whether to apply treatment or forego it.

Materials and method

The Australian researchers sent their questionnaire directly to obstetricians and paediatricians practising in the State of Victoria, receiving replies from 87 obstetricians (some 30 per cent of all active obstetricians in that State) and 111 paediatricians (44.4 per cent). Since we had no similar list, we sent 200 questionnaires to fifteen of the largest hospitals and clinics in Warsaw (including the well-equipped Children's Health Centre), addressing the envelopes to heads of intensive-care, neonatal and related hospital departments. The forms were mostly sent back unsigned to one of the authors' addresses. We received 74 completed forms from only seven of the fifteen hospitals and clinics approached. Unlike the Australian team, we conducted no interviews. But some envelopes sent to us included, apart from the completed forms of the questionnaire, detailed letters emphasising the significance of the issue or raising various objections. Since we do not know the exact number of paediatricians on the staffs of Warsaw hospitals and clinics, we cannot establish to what extent our findings are representative for the entire community of paediatricians in Warsaw. But our findings no doubt reflect the opinions of a large majority of paediatricians working in the seven health-care centres which responded. It is remarkable that as many as eight other centres ignored our questionnaire. This fact perhaps reveals either a poor opinion of this kind of study or a failure to recognise the significance of the issues. We are unable to say which of these was the decisive factor.

Key words

Handicapped infants; euthanasia; neonatal terminal care; 'ordinary' and 'extraordinary' means; respect for life; parents' consent; comparative medical ethics.

Results and discussion

A clear majority of doctors in both Australia and Poland said they had faced cases in their practice when a decision had to be made on whether to go on with or to discontinue treatment (90.1 per cent among the Australian doctors, 78.4 per cent among the Poles). But they differed significantly on the question of what should be done in such situations. Only two Australian paediatricians (1.8 per cent) believed all possible steps should always be taken to sustain lives of newborn infants with serious handicaps, while the remaining 98.2 per cent said that was not necessary. The Polish paediatricians proved to be more traditionally-minded; on an exactly fifty-fifty split of responses, 37 of them said they would try anything to preserve lives of newborn infants while 37 said that was not necessary. The two Australians who were willing to save infants at all cost justified their position – one invoking secular moral principles, the other religious injunctions. Of the 37 Polish doctors pledging a willingness to save infants' lives at all costs, 23 (31.1 per cent) justified their view by reference to secular ethical standards while 14 (18.9 per cent) indicated religious ethics.

TABLE 1

	Paediatricians (Victoria) (N = 111)		Paediatricians (Warsaw) (N = 74)	
	Yes	**No**	**Yes**	**No**
1. In the course of your medical practice have you ever had cases in which decisions have had to be made whether or not to continue the treatment of a severely handicapped infant?	100 (90.1%)	11 (9.9%)	58 (78.4%)	16 (21.6%)
2. Do you believe that in all circumstances every possible effort, including the use of both ordinary and extraordinary means, should be made to sustain life?	2 (1.8%)	109 (98.2%)	37 (50%)	37 (50%)
3. If you answered 'yes' to Question 2, would you describe your belief as based primarily on				
(a) secular moral principles	1 (0.9%)		23 (31.1%)	
(b) ethical principles deriving from religious views	1 (0.9%)		14 (18.9%)	
(c) Other? please specify. Medical ethics and practice (Hippocratic Oath)	–		6 (8.1%)	
4. Where a decision has to be made whether or not to continue treatment, do you discuss what should be done with				
(a) another doctor or doctors?	101 (90.9%)		73 (99.0%)	
(b) the parents?	100 (90.1%)		6 (8.1%)	
(c) nursing staff?	94 (84.7%)		3 (4.3%)	
5. In deciding whether or not to continue treatment, do you think it important to distinguish between 'ordinary' and 'extraordinary' means of prolonging life?	86 (77.5%)	25 (22.5%)	23 (31.1%)	32 (43.2%)
			No answer	19 (25.7%)
6. Have you ever directed that less than maximum efforts should be made to preserve the life of an infant? Has this happened				
(a) several times	53 (47.8%)		5 (6.8%)	
(b) occasionally	30 (20.0%)		11 (14.9%)	
(c) once or twice	9 (8.1%)		12 (16.2%)	
(d) never	12 (10.8%)		31 (41.9%)	
(e) no answer	7 (6.3%)		15 (20.2%)	
7. Do you believe that there can ever be circumstances in which it is right to take active steps to terminate the life of an infant, ie steps that go beyond the withdrawal of life-support systems?	44 (39.6%)	61 (54.9%)	1 (1.3%)	60 (81.1%)
	No answer	6 (6.6%)	No answer	13 (17.6%)
8. Do you see a need for change in the law relating to the treatment of severely defective infants?	50 (45.0%)	50 (45%)	9 (12.2%)	37 (50.0%)
	No answer	11 (12.2%)	No answer	28 (37.8%)

Apart from these, six Polish doctors mentioned medical practice and ethics, specifically referring to the Hippocratic Oath, as the moral grounds for their beliefs. The problem is that the Hippocratic Oath (assuming of course, Hippocrates formulated it) says nothing about treating newborn infants with serious physical or mental defects while the rule attributed to Hippocrates, *primum non nocere*, has nowadays come to be occasionally interpreted as an ethical justification of euthanasia of such patients (2). So, it is by no means certain that the injunction to save the lives of terminally ill patients can be derived from the Hippocratic Oath. It is equally debatable if such an attitude can be morally justified by reference to medical practice in an abstract sense. The case of medical practitioners in Australia alone suffices as evidence, because only two doctors were willing to prolong life at any price, so if the results are representative this is obviously not the most common medical practice in that country (Table 1, questions 1–3).

Surprising answers were received to the question about how decisions on terminating or prolonging lives of newborn infants should be made. More than 90 per cent of the Australian doctors regarded it as their duty to consult about such decisions with their colleagues and with the infant's parents, and as many as 84.7 per cent of them believed that nurses' opinions should be taken into consideration. In contrast, while 99 per cent of the Polish doctors thought such decisions should not be made without consulting other doctors, they were in general clearly unwilling to consult parents or nurses, for only six doctors (8.1 per cent) said they would take into account what the parents said, and only three (4.3 per cent) would care to listen to what nurses had to say (Table 1, question 4). This disparaging attitude towards nurses' views is perhaps due to the relatively low prestige of this occupation in Poland. But what about the baffling contempt for parents' opinions? Most of our sample of Polish doctors, it seems, tend to regard this kind of treatment as a purely medical decision which competent professionals alone can discuss and make. As they are not perceived to fall into the category of competent professionals, nurses and parents are believed to have no say in such cases. Polish doctors clearly fail to understand that being an authority on medical matters does not make one an authority on moral matters. Conversely it seems to be increasingly recognised in Western medical practice that as far as moral issues are involved, a baby's parents as well as nursing personnel are indeed legitimate partners for discussion, and major decisions on a baby's health or life seem not so readily to be made without the knowledge and consent of parents or people authorised to take care of the baby. When parents refuse their consent for what doctors believe is

TABLE 2

Answers to the question: 'What, in your view, are "extraordinary" means of prolonging life?'

ANSWER	Paediatricians (Victoria) (N = 111)	Paediatricians (Warsaw) (N = 74)
Intensive care and the prolonged use of modern life-support systems	89 (80.2%)	12 (16.22%)
Intensive blood transfusions	7 (6.3%)	1 (1.35%)
Pacemaker	6 (5.4%)	1 (1.35%)
Heroic surgery	14 (12.6%)	3 (4.05%)
Antibiotic agents	12 (10.8%)	–
Humidicrib	–	–
Everything except warmth, fluid, demand feeding and sedatives if necessary	1 (0.9%)	2 (2.70%)
Renal dialysis	12 (10.8%)	1 (1.34%)
IV feeding	–	4 (5.4%)

Note
53 (71.62%) of the Polish paediatricians did not answer this question. It is not clear how many Australian doctors replied, but clearly at least 89 (80%) did so.

a necessary operation, or when they oppose further attempts to prolong life, the decision may be made by a court. Karen Quinlan was a well known-case in point (3).

Polish doctors apparently believe they can make decisions on their own without parents' consent. This may well be one unexpected side-effect of the health service's nationalisation, but it may also be a reflection of Polish society's comparatively poor legal and moral consciousness and of the fact that the medical community is subject virtually to no public control.

Comparison with the Australian study revealed a significant difference in replies to a question about the legitimacy of distinguishing between 'ordinary' and 'extraordinary' means of prolonging life (Tables 2 and 3). As many as 78 per cent of the Australian paediatricians involved in the survey said this distinction was important and necessary, even though some of them recognised antibiotics, humidicribs or pacemakers as ordinary while others saw them as extraordinary means of prolonging life. In contrast to this, Polish paediatricians were very sceptical about this particular distinction. Only 23 people (31.1 per cent) believed this to be an important and necessary distinction in medical practice, whereas the others either flatly denied this (43.2 per cent) or declined to answer (25.7 per cent). Like their Australian counterparts, those 23 who replied in the affirmative mentioned no clear and unambiguous criterion for drawing the distinction between 'ordinary' and 'extraordinary' means of prolonging life. Four Polish paediatricians described intravenous feeding as ordinary means; the same number described it as extraordinary means. However, hardly any of the Polish doctors cited examples of the two kinds of means of prolonging life.

This inability of both Australian and Polish paediatricians to come forward with a clear standard to distinguish ordinary from extraordinary means of prolonging life is not really surprising. It is precisely this difficulty of saying what is and what is not an extraordinary means that has made this distinction recently lose ground in medical practice in favour of criteria such as quality of life or cost-benefit analysis (4). What is surprising is that as many as 53 (or 71.62 per cent) of the Polish paediatricians declined to answer the two questions about this distinction. Considering that Poland is a nation clearly dominated by Catholic ethics, and that the distinction between ordinary and extraordinary means of prolonging life is a Roman Catholic doctrine and recognised officially in Catholic medical ethics, it seems that Polish doctors are either unfamiliar with the Catholic moral doctrine or they largely ignore it. But then it cannot be ruled out that other considerations, mostly social and economic ones, are obliterating the difference between ordinary and extraordinary means of prolonging life in their minds (admittedly, nobody has yet established the extent of Catholic ethics in the Polish medical community). For example, since it is unclear just who is paying for the treatment, it may be thought that virtually everything becomes an ordinary means. On the other hand, amidst the present acute shortage of medicinal equipment or drugs it may be that even the crudest drugs or equipment would be regarded as extraordinary means.

TABLE 3

Answers to question: 'What, in your view, are "ordinary" means of prolonging life'?

ANSWER	Paediatricians (Victoria) (N = 111)	Paediatricians (Warsaw (N = 74)
Pacemaker	1 (0.9%)	–
Antibiotic agents	16 (14.4%)	1 (1.35%)
Normal nursing care, including fluids	46 (41.4%)	8 (10.8%)
Humidicrib	–	4 (5.4%)
IV feeding	–	4 (5.4%)
Easily accessible or universally applied drugs and techniques	–	6(8.1%)
Chemotherapy/including painkillers	–	6(8.1%)

Note
53 (71.62%) of the Polish paediatricians did not answer this question. At least 46 (= 41.4%) of the Australian paediatricians replied.

TABLE 4

Answers to the question: 'Under what circumstances do you consider that less than a maximum effort should be made to preserve the life of an infant?

ANSWER	Paediatricians (Victoria) (N = 111)	Paediatricians (Warsaw) (N = 74)
General principles		
Incompatibility with reasonable and independent life	21 (18.9%)	15 (20.3%)
Multiple severe congenital abnormalities providing life-long suffering for patients and family	5 (4.5%)	13 (17.5%)
Inevitable early death	30 (27.0%)	13 (17.5%)
Answers included the following examples:		
Anencephaly and microcephaly	33 (29.7%)	7 (9.4%)
Spina bifida and meningomyelocele	28 (25.2%)	1 (1.3%)
Extreme prematurity	10 (9.0%)	7 (9.4%)
Down's syndrome with other lesions	18 (16.2%)	–
Brain damage and mental retardation	29 (26.1%)	15 (20.3%)
Irreversible heart damage	–	2 (2.7%)

A comparison of replies supplied by the Australians and the Poles to the question: 'Under what circumstances do you consider that less than a maximum effort should be made to save the life of an infant' revealed interesting differences of view. 18.9 per cent of the Australians and 20.3 per cent of the Poles said all efforts should be discontinued when the infant was incapable of meaningful independent life. But 17.5 per cent of the Poles, compared with only 4.5 per cent of the Australians, believed that the same applied to newborns with multiple severe handicaps which might cause suffering for the patient and the parents (Table 4). This table reveals the curious fact that diseases which the Australian paediatricians regard as either incompatible with reasonable and independent life and/or associated with lifelong suffering for patients and families and/or with inevitable early death (spina bifida and myelomeningocele as well as Down's syndrome in connection with other congenital abnormalities) were rarely mentioned by the Polish paediatricians. The standard procedure in such cases may therefore be to take all steps to sustain the baby's life at all costs. One way or another, this is a point which deserves to be looked into. One thing at least is sure – when they decide to discontinue treatment, many Australian and Polish doctors are guided by the quality of a patient's life in the future rather than by possibilities of preserving his or her life using either 'ordinary' or 'extraordinary' means.

A comparison of replies to questions 6 and 7, Table 1 ('Have you ever directed that less than maximum efforts should be made to preserve the life of an infant?' and 'Do you believe that there can ever be circumstances in which it is right to take active steps to terminate the life of an infant, ie steps that go beyond the withdrawal of life-support systems?') revealed a significant difference of view between the Poles and Australians on the matter of treating infants who are virtually incapable of surviving. As many as 53 (or 47.8 per cent) of the Australian doctors ordered several times in their practice to discontinue treatment, that is, resorted to passive euthanasia, compared with only five (6.8 per cent) Polish doctors. 12 Australians (10.8 per cent) and 31 Poles (41.9 per cent) never did that. In reply to question 7, 44 (39.6 per cent) of the Australians believed that in some situations a doctor has a right to resort to active euthanasia (Table 1, questions 6 and 7). Among the 74 Polish doctors embraced by the survey, only one said active euthanasia may be acceptable in certain circumstances, while a clear majority of 60 (or 81.1 per cent) were

against all active steps in such cases. Some Polish doctors (17.6 per cent) declined to answer this question, which may point to their unease about what should be done. Perhaps this difference in attitudes of doctors in the two countries can be explained by different views of what life actually means. Polish doctors tend to abide in their work by the principle of respecting all life and refraining from evaluating it. The Australian doctors, on the other hand, consider life from the vantage point of its quality, and acknowledge the possibility that, under certain strictly defined circumstances, prolonging a patient's life may be harmful for the patient himself.

Replies of the Polish paediatricians to question 8, Table 1 ('Do you see a need for changes in the law relating to the treatment of severely defective infants?') are difficult to interpret. 12.2 per cent of all respondents wanted certain changes, 50 per cent expressed a conservative view failing to see such a need, while 37.8 per cent declined to answer. The problem is that in Poland there are no specific regulations concerning treatment of infants with serious congenital and irreversible defects. The 1969 Penal Code stipulates generally: 'Who slays a person at this person's demand, and under the influence of sympathy for this person, is subject to imprisonment for six months to five years'. This provision clearly bans certain forms of euthanasia. But since doctors and lawyers commonly interpret this provision as applying only if there is somebody who demands his life to be terminated and somebody else who terminates that life (5), this provision obviously does not hold for newborn babies, who cannot possibly express their demands. Some doctors (Professor J Bogusz, for example) describe termination of treatment of a seriously handicapped newborn infant not as a case of euthanasia but as ordinary homicide (6). But it is also legitimate to argue that the life of some creatures, say such as acranii, is no life at all and hence is not protected by law (7).

However, there are no unequivocal legal provisions defining a doctor's rights and duties in treating infants with severe defects. So, what can one make out of the above figures? It seems that those 50 per cent of Polish doctors who want no changes in the binding law relating to the treatment of severely defective infants are unwittingly extending existing legal regulations also to cases of infants, and failing to realise that severely defective infants may have a different legal and moral status from normal healthy infants. This, incidentally, would be a straightforward consequence of a principle persistently brought home to all Polish doctors, namely that 'preserving human life is the principal duty of a doctor. Struggle for a patient's life until all available means have been exhausted is among a doctor's noblest duties. Deliberate and purposeful steps to cause death are incompatible with this essential principle of the medical profession' (8). On the other hand, it is really upsetting to find in some forms replies such as 'I'm not interested in legal clauses', 'I don't know legal regulations', or 'Ethical criteria along with an estimate of an infant's chance of survival are the only things I consider in my work'. The present situation was perhaps best summed up by one of our respondents, who wrote: 'It is difficult to change regulations which do not exist or, if they do, then they are not functioning, especially in relation to newborn infants'. So, we have clearly arrived at a point at which a broad discussion should be started and definite legal action should be taken to establish certain legal norms in this area.

Conclusions

Our comparison of attitudes of Australian and Polish doctors has disclosed important differences in approach to terminally ill newborn babies, their parents, medical personnel and the binding law. Australian doctors facing morally significant decisions tend to take account above all of the quality of the infant's future life, and, while largely endorsing passive euthanasia (discontinuation of treatment), they display more understanding and tolerance towards active euthanasia. In the Polish medical community surveyed, unconditional respect for life is a more dominant attitude. If life is a sacred value, it must not be shortened deliberately or purposefully, and therefore half of the Polish doctors would be willing to preserve the lives of severely defective newborn infants at all costs. Our study has revealed a deeply-entrenched paternalistic attitude among Polish doctors, a strong unwillingness to distinguish between 'ordinary and extraordinary' means of prolonging life, as well as an ambivalent attitude towards legal regulations binding in Poland. The Australian doctors surveyed seemed to be familiar with legal regulations and to take clear, positive or negative, attitudes towards them. In contrast, most of the Polish doctors in our survey seemed either unaware of or defiant of the relevant law.

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News and notes

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